

A delicate balance: negotiating renal transplantation, immunosuppression and adherence to medical regimen

Cook, Peta S.; McCarthy, Alexandra

Postprint / Postprint

Zeitschriftenartikel / journal article

Zur Verfügung gestellt in Kooperation mit / provided in cooperation with:

www.peerproject.eu

Empfohlene Zitierung / Suggested Citation:

Cook, P. S., & McCarthy, A. (2007). A delicate balance: negotiating renal transplantation, immunosuppression and adherence to medical regimen. *Health*, 11(4), 497-512. <https://doi.org/10.1177/1363459307080875>

Nutzungsbedingungen:

Dieser Text wird unter dem "PEER Licence Agreement zur Verfügung" gestellt. Nähere Auskünfte zum PEER-Projekt finden Sie hier: <http://www.peerproject.eu> Gewährt wird ein nicht exklusives, nicht übertragbares, persönliches und beschränktes Recht auf Nutzung dieses Dokuments. Dieses Dokument ist ausschließlich für den persönlichen, nicht-kommerziellen Gebrauch bestimmt. Auf sämtlichen Kopien dieses Dokuments müssen alle Urheberrechtshinweise und sonstigen Hinweise auf gesetzlichen Schutz beibehalten werden. Sie dürfen dieses Dokument nicht in irgendeiner Weise abändern, noch dürfen Sie dieses Dokument für öffentliche oder kommerzielle Zwecke vervielfältigen, öffentlich ausstellen, aufführen, vertreiben oder anderweitig nutzen.

Mit der Verwendung dieses Dokuments erkennen Sie die Nutzungsbedingungen an.

gesis
Leibniz-Institut
für Sozialwissenschaften

Terms of use:

This document is made available under the "PEER Licence Agreement". For more Information regarding the PEER-project see: <http://www.peerproject.eu> This document is solely intended for your personal, non-commercial use. All of the copies of this documents must retain all copyright information and other information regarding legal protection. You are not allowed to alter this document in any way, to copy it for public or commercial purposes, to exhibit the document in public, to perform, distribute or otherwise use the document in public.

By using this particular document, you accept the above-stated conditions of use.

Mitglied der

Leibniz-Gemeinschaft

A delicate balance: negotiating renal transplantation, immunosuppression and adherence to medical regimen

Peta S. Cook and Alexandra McCarthy

Queensland University of Technology and Griffith University, Australia

ABSTRACT Despite the volume of biomedical and psychosocial discourse surrounding both renal transplantation and the immune system, there is a limit to current understandings of immunosuppression in the context of kidney transplantation. For example, we do not know how the immunosuppressed renal transplant recipient experiences and understands their immune system and body. In addition, we do not know if the patient is as fixated on ‘graft survival’ as their healthcare team or whether other concerns are more relevant. What is missing is the discourse of those who actually ‘live’ the medically altered immune system in the context of renal transplantation.

We propose that this gap in knowledge is bound to an acknowledged problem among renal transplant recipients and their healthcare teams – a lack of compliance with recommended medical regimens. Our argument here is that an exploration of patient intimacy with transplant-related immunosuppression might illuminate a different understanding of this experience that could enhance health professionals’ understanding and their subsequent approach to treatment. We contend that the embodied and contextual experience of the patient needs to be equally valued in order to enhance patient outcomes.

KEYWORDS *compliance; embodiment; immunosuppression; renal; transplantation.*

ADDRESS Peta S. Cook, QUT Carseldine, E block, Beams Road, Carseldine, QLD 4034, Australia. [Tel: +61 7 31384780; fax: +61 7 31384719; e-mail: p2.cook@qut.edu.au]

ACKNOWLEDGEMENTS We would like to thank Dr Margaret Gibson and Mr Ramon Shaban for their comments on earlier versions of this article.

Introduction: Biomedical perspectives of renal transplantation and immunosuppression

From the biomedical perspective, transplantation is the ‘transfer of living cells, tissues or organs from a donor to a recipient, with the intention of maintaining the functional integrity of the transplanted material in the recipient’ (*Merck manual*, 2006a). Renal transplantation, which involves the grafting of either live or cadaveric kidneys into a recipient body, is the treatment of choice for individuals in end-stage renal failure. This procedure obviates the time-consuming, lifestyle-constricting and costly dialytic procedures that are otherwise necessary to clear the body of accumulated wastes in the absence of functioning kidneys.

From the perspective of health professionals working in the area of organ transplant, ‘survival’ following renal transplantation is dependent on the host body accepting the donated ‘alien’ tissue. Such acceptance relies on the inhibition of the body’s immune reaction to prevent the rejection of the donated kidney. This pharmaceutically induced suppression of physiological difference between host and donor, has made organ transplantation a viable treatment. The judicious use of immunosuppressive drugs, coupled with constant immunological surveillance of kidney recipients for the life of the donated organ, has resulted in standard renal transplant survival rates of between 70 and 90 per cent one year after transplant (*Merck manual*, 2006c). There have also been reports of functioning grafts up to 30 years after the procedure (*Merck manual*, 2006c). In theory, the dosage of immunosuppressive agents is delicately balanced between selective repression of the immune system to ensure graft survival, and ensuring some degree of immune protection against disease. The obvious and unfortunate consequence of this practice, however finely tuned, is the immunosuppressed body inevitably becomes open to infections and diseases that can lead to the death of transplant recipients (Brenner et al., 2002; *Merck manual*, 2006b). Some of these drugs also have considerable toxicities that are not well tolerated by patients. Their side-effects include, but are not limited to, oedema, systemic hypertension, hyperlipidemia, diabetes, mood and sleep alteration, high blood pressure, renal insufficiency, infection, obesity, osteoporosis, gastric ulcers and various malignancies (Sherwood, 1993; Burke, 2003; Green, 2003; Fireman et al., 2004). Inherent in the great care taken to balance these issues is recognition that the post-transplant recipient teeters continuously and precariously between organ rejection and infection.

Understandably, given the acknowledged biomedical focus on maintaining the functionality of transplanted material in the organ recipient (*Merck manual*, 2006d), the compliance of patients to a medical regimen for graft preservation is of constant concern to health professionals. Renal patients in general are not notable for their compliance with pre-transplant medical regimens, let alone post-transplant medical regimens. Unsurprisingly, non-compliance is the most commonly cited reason for graft failure

(Chisholm et al., 2001; Kreiger and Emre, 2004; Moloney et al., 2005). We believe that there are two reasons for this.

First, the patient's understanding of the immune system is largely filtered through the lens of biomedical science, involving macrophages, antibody-antigen complexes, renal insufficiency and disturbed metabolisms. This complex language is fashioned from a closed biomedical field by select practitioners who work in that field. Like the immune system, renal systems are biomedical constructs, assembled and maintained through biomedical knowledges and technologies (Haraway, 1991). This establishes a strict boundary between transplant science and the patient, with scientific knowledge often provided to the patient in a supposedly attenuated, easily digested form by the healthcare professional. The aim is to provide some kind of scientific and medical literacy to enhance patient compliance to medical regimens. Additionally, patients and the lay public are 'educated' on science and medicine through the media. The media and their portrayal of these issues is an extremely important source of public information, but one that does not necessarily provide a comprehensive picture. Hence, in this initial framework, compliance is related to patient levels of knowledge and understanding. We will return to this later.

Second, and most importantly, while these biomedical discourses are valid, there is more to the experience of transplant-related immunosuppression and adherence to medical regimen than 'graft survival'. This connects to the lived experience of 'being' an immunosuppressed body. The literature on this is sparse, though sociologists and anthropologists of biomedicine have come some way to providing some understanding. In the process, they have provided invaluable insights that might enhance clinicians' comprehension of what it means to adhere to immunosuppressive regimens. This article explores these issues in terms of the immune system and the maintenance of social order; and the post-transplant body. It should be noted that this exploration is a theorization of existing literature. In the future, we plan to expand this to an empirical examination. The aim of our analysis here is to indicate significant gaps in the field, which, we believe, compromise the treatment and care of individuals who experience a compromised immune system, particularly post-transplantation. Empirical research is particularly lacking with respect to embodiment and the subjective, private post-transplant body. As such, this article covers significant ground, drawing attention to the complexities of transplantation, immunosuppression and compliance; a complexity that is heightened by tensions that may exist between the social, biological and material bodies.

The immune system and the maintenance of social order

There have been numerous sociological and anthropological explorations of the healthy immune system (for example, Haraway, 1991; Martin, 1994). While none of these studies focus specifically on immunosuppressed renal

transplant patients, they are none the less useful for our present purposes. This is because they expose the biomedical discourse of the immune system as saturated with aggressive and coercive imagery, which may influence the way healthcare professionals and patients alike approach post-transplant medical regimens. Additionally, these examinations highlight strong omissions in our understandings of immune system 'experiences'.

In Western thought, social order has long been a significant concern, and the healthy body has often functioned as a metaphor for a politically healthy society. The body operates as a robust image for social pathology, as it represents the structure and function of society as a whole (Otis, 1999; McCarthy, 2005). The discourse of the immune system provides the analyst with a particularly rich field in this respect. Martin (1994), for example, describes how the media position the immune system as the chief defender of the body. In such frameworks, the body is articulated as a machine, with the immune system maintaining and preserving the sanctified police-state or nation-state of the body. In these discourses, three consistent socio-political themes emerge: martial imagery and the requirement for internal bodily surveillance and policing; the body as a regulatory communications network; and the hierarchy of labour divisions to maintain nation-state integrity. These categories provide a coherent framework that affords some understanding of how the immune system has been constructed and how the immunosuppressed renal transplant recipient may interpret and understand their own situation. We will now examine these socio-political themes in turn.

Martial imagery

The body is consistently portrayed by the media and healthcare professions as a revered nation-state vulnerable to the threat of the 'foreign', as embodied in the 'other' (Martin, 1994). Strict borders are drawn between self and non-self, which are patrolled and protected by a hyper-alert immune system. In these portrayals, the body is a martial nation-state at war with hostile and polluting agents. Constant vigilance, defence and retaliation are the obvious responses to non-self entities that dare to invade the body's external borders. Dwyer (1993), writing from the biomedical perspective, draws on this imagery repeatedly. For Dwyer, the immune system consists of a series of security systems, forces and checkpoints, which protect 'the sacrosanct environment of a body' (1993: 33). These self-preservation techniques additionally involve metaphors such as guard dogs, barbed wire, spotters, bouncers and identity checks (Dwyer, 1993). Every native cell in this policed body is equipped with a proof of identity that protects it against attacks from the body's own defence mechanisms, while intruder 'records' are stored in the vast archives of the immune system's memory cells (Dwyer, 1993; Martin, 1994). The potency of this imagery is reinforced by the section titles of Dwyer's (1993) text, including 'The War and the Warriors', 'Taming

the Warriors', 'The Defeat of the Warriors', 'Where are the Generals?' and 'Assisting the Warriors'. The brutal power of this metaphorical discourse is perhaps no more vivid than in the following:

Quite destructive soldiers, kept for this purpose [to deal with an 'intruder' demonstrating 'destructive behaviour'], would seize upon the hapless violater [*sic*] and kill him with a combination of chemicals and repeated stabbings – the security business is not a pretty one. (Dwyer, 1993: 35)

Communication networks

In addition to these martial metaphors, Martin's (1994) analysis also makes it clear that this nation-state is not controlled by one organ alone. It is a 'kind of biologic democracy, wherein the individual members achieve their ends through an information network of awesome scope' (Jaret, 1986 in Martin, 1994: 415). The role of communication in this nation-state is paramount. The immune system takes on this role, operating as the body's regulatory communications network: a sophisticated and fluid configuration of command-control-communication-intelligence (C3I) (Haraway, 1991; Martin, 1994). The cunning specificity of this network means intruders who do not speak the language are subject to mechanisms of control through extermination. Hence, the immune system's communicative role of identifying self and other is vital for the militaristic immune activities. In this fashion, 'the immune system is a plan for meaningful action to construct and maintain the boundaries for what may count as self and other in the crucial realms of the normal and the pathological' (Haraway, 1991: 204). Martin (1994) argues the outcome of this is a discourse permeated with imagery of force and control, which in effect domesticates violence and makes aggression seem an ordinary and natural part of daily life. We would argue that this aggression and violence also justifies the severity of many medical practices in immunosuppression and transplantation. In turn, such approaches heighten the medical construction of body-as-machine (the disembodied object) in preference to the body-as-self (the embodied subject).

Labour divisions

All nation-states, including bodily democracies, tend effectively to function primarily through hierarchical divisions of labour. In immune system discourses constructed by the media and biomedicine, these hierarchies tend to be informed by the traditional, stereotypical gender differences of the wider body politic (Martin, 1994). This includes performing work often associated with the masculine ethos of the clinic. Thus, as Martin (1994) demonstrates, the T- and B-cells, which are positioned in these discourses at the apex of the immune system hierarchy, are portrayed as masculine. Their war-like actions include killing intruders through phallic activities of penetration and injection. T-cells are also posited as highly specialized, tactical and almost intellectual entities, who orchestrate the defensive system

and store memories of past enemies for future reference (Martin, 1994). In contrast, lower-ranking members of the hierarchy, such as phagocytes and macrophages, assume a distinctly feminine cast (Martin, 1994). Their feminine work, which reflects the labour of household maintenance, involves the drudgery of cleaning up or engulfing foreign particles (Martin, 1994). They are also stereotypically female and motherly in their self-sacrifice on behalf of bodily integrity when confronted with threatening invaders. The longstanding association of the female and the uncivilized that has been well explicated in feminist theories (for example, see Birke, 1994; Birke et al., 2004; McCarthy, 2005) is also evident in immune system discourse that describes their other lower order function of cannibalizing dangerous parts of the self.

These biomedical portrayals of the immune system as a violent and gendered communication network may place the renal patient, who has their immunosuppression induced as a life-saving measure, in an ambiguous position. For example, one individual in Martin's study visualized the immune system as an attacker, designed to protect the body's boundaries from external assault: 'your body is going to get ready to defend itself and destroy the bad stuff, the bad guys' (1994: 177). When given the opportunity, however, individuals may employ other imagery, particularly related to the more benign aspects of political networks. This includes metaphors of flow and flux that predicate the immune system as a constant that is everywhere and nowhere in the body; a responsive agent that is subject to variation and change (Martin, 1994). Therefore, while the lay person may not have a purely biomedical understanding of the immune system, they can demonstrate an understanding of its complexities and ambiguities. In other words, while their comprehension is not framed by rigid biomedical 'fact', they do have an understanding that involves complex human issues and expertise (Claeson et al., 1996). The public account and negotiation of illness, however, can be different to private accounts of experiencing illness. Importantly, the way people engage in this 'talk' is vital for the bodily experience of self (Kelly and Field, 1996). Thus, it is reasonable to surmise that the immunosuppressed individual may have their own ways of understanding the immune system, which are beyond medical understandings of immune system biology, and are influenced by their own experiences, knowledges of and interactions with the world (Claeson et al., 1996).

While these studies are fascinating explorations of immune system perceptions, they are mostly conceptualized by those who are neither transplant recipients nor immunocompromised. This highlights a significant gap in knowledge. Namely, we are missing perceptions and possible ambiguities of the medically-altered immune system by those who intimately experience its functions and alterations. We do not know how immunocompromised individuals understand or construct the immune system, let alone how they understand and construct their bodies in the immunosuppressed state. Such individualized negotiations and embodied experiences are undoubtedly

significant for the healthcare profession and professional. This knowledge gap may compromise patient treatment and their quality of life. A major problem in current knowledge therefore is a lack of empirical research. What this also highlights is that while it is important to understand how people who are immunocompromised view the immune system, it is also important to understand their diverse relations and the contextual experiences of their embodied selves in such a state. Consequently, we wish to explore the literature detailing the possible challenges in living with a post-transplant, immunosuppressed body. This is divided into two concerns: the objectified and medicalized body; and the subjective and private body. The first point relates to how medicine understands the post-transplant body, which is often framed around compliance rhetoric. The latter, with a focus on the 'lived' social and material body is often viewed in direct opposition, though no existing literature specifically deals with these issues. These considerations illustrate a complex network of immunosuppression, transplantation, compliance and contextual experiences of the body. Again, we focus on a theoretical examination of existing literature in order to emphasize the shortcomings in existing knowledge.

The objectified and medicalized post-transplant body

As noted previously, post-transplant immunosuppression may cause significant side-effects for the patient, such as infection and treatment-related disease. Pharmaceutically induced immunosuppression can therefore create further health problems or exacerbate existing ones, which may adversely affect quality of life and familial relationships. Such experiences highlight complex psychosocial problems associated with pre- and post-transplant adjustments, which include lifestyle adaptations that can alter relations between self, family and others (Rauch and Kneen, 1989). In addition, complex emotions accompany the wait and the receipt of a donated organ. These emotional states, which can be exacerbated by immunosuppressive drugs, have led to over 50 per cent of transplant recipients reporting mood changes, adjustment disorders, depression, post-traumatic stress, delirium and psychiatric problems (Rauch and Kneen, 1989; Fukunishi et al., 2001; Jowsey et al., 2001; Dew et al., 2004).

Due to these numerous post-transplant challenges, it is not surprising that psychosocial and clinical research is primarily concerned with understanding those aspects believed to influence directly the patient's post-transplant quality of life, namely patient non-compliance with medical regimens. The enormous amount of literature on these topics indicates their intense interest to healthcare researchers and providers (Martins, 2005). We will now briefly explore a small selection of this research.

As stated previously, renal patients are not noted for compliance with pre- or post-transplant regimens. In general, patient non-compliance with rigorous medical regimens and lifestyle changes are believed to be

prevalent in post-transplant recipients (Jowsey et al., 2001), with Laederach-Hofmann and Bunzel (2000) reporting a 20–50 per cent non-compliance rate. As a result, the issue of patient compliance with medical regimens, which is variously referred to as adherence, commitment or concordance, is among the most voluminous, yet least understood, in renal and transplant literature. Compliance research centres on patient behaviours that increase infectious risk or pose a threat of transplant rejection. For example, Donovan et al. (2004) found that despite an increased risk of immunocompromised post-transplant recipients developing skin cancer, only 18 per cent of 205 transplant recipients practise adequate levels of sun-protective behaviours, with 23 per cent continuing to seek a suntan. Consequently, ‘between 35–50% of transplant recipients will develop one or more skin cancers by the tenth year following organ transplantation’ (Donovan et al., 2004: 1852).

Generally, ‘transplant patients tend to be divided into those who comply with the treatment regime and those who do not’ (Baines et al., 2005: 43). In order to identify and circumvent patient non-compliance post-transplantation, Wilkins et al. (2003) advocate holistic approaches focused on patient survival, rather than graft survival. In this approach, patient empowerment is fostered by building relationships with healthcare professionals and through targeted education programmes. It is argued this facilitates a return to normalcy, which, by default, promotes graft endurance (Wilkins et al., 2003). Similarly, Bunzel and Laederach-Hofmann (2000), Levenson and Olbrisch (2000) and Baines et al. (2005) believe patient non-compliance with medical regimens can be identified, circumvented or interceded through detection methods such as psychosocial profiling or screening. It is claimed these interventions are holistic, providing education and psychological support so patients can demonstrate their ability to comply pre-transplantation (Bunzel and Laederach-Hofmann, 2000; Levenson and Olbrisch, 2000), or to shift their behaviour towards compliance and emotional stability post-transplantation (Baines et al., 2005). We would argue, however, that these interventions are framed around subjective and ambiguous judgements on behalf of the healthcare profession. For example, it is pre-determined ‘whether the patient can be sufficiently educated for the transplant patient role’, and ‘will be able to form a collaborative relationship with physicians and comply with the medical regimen’ (Levenson and Olbrisch, 2000: 23).

In these frameworks, patient non-compliance is perceived as an adaptive challenge that requires medical intervention through active patient co-operation. Educational programmes are aimed at creating psychosocial adjustment so that the patient will accept and deal with their immunosuppressed post-transplant condition in what is deemed to be an appropriate medical manner. This may involve psychological counselling. Hence, non-compliance is reframed as a mental illness. Furthermore, as patient non-compliance is viewed as a waste of precious resources, reasons for patient non-compliance are continuously sought. As a result, recent research has attempted to identify variables that lead to patient non-compliance to

circumvent or predict the need for medical intervention. For example, Bunzel and Laederach-Hofmann (2000) identify non-compliance as determined by demographic and psychological variables, psychiatric disorders, poor social support, obesity, substance abuse and health-related factors. Irrespective of patient control over any of these variables however, failure to comply is often directly or indirectly placed on the patient, who is ultimately held responsible for medical non-compliance and any associated behaviours.

Regardless of the intervention strategy adopted, these are often not very effective in increasing compliance rates. As indicated previously, patient non-compliance is a commonly reported problem in pre- and post-transplant recipients by healthcare professionals. Generally, patients are well informed and knowledgeable about their medications and the consequences of their actions (Laederach-Hofmann and Bunzel, 2000), meaning education programmes targeted at producing or enhancing compliance could be viewed as nonsensical. Patient non-compliance may have nothing to do with adherence to or the difficulties of medical regimens. For example, the individual might be asserting themselves in the face of medicalized control and power. Perhaps part of this continued healthcare professional impulse to counter patient non-compliance arises from biomedical militaristic metaphors of the immune system and the body as nation-state. Shildrick argues the 'issue of vulnerability, of controlling and eliminating the risk of weakness, ... marks the immunocompromised body as a shortcoming' (2001: 156). From this perspective, immune deficiency marks the transplant patient as not only vulnerable but abnormal, operating contrary to the biological and societal standards of the nation-state. In other words, the threat of an immunosuppressed body lies in the transgression of boundaries, 'in being irreducibly other to the binary self' (Shildrick, 2001: 159). The irony for the immunocompromised renal transplant recipient is their immunodeficiency, their 'abnormality', is deliberately induced to ensure graft survival and their survival.

Despite extensive research, which has mostly been defined in clinical terms, reasons for patient non-compliance are difficult to identify. It is our argument that this lack of biomedical understanding is partially linked to a failure to acknowledge subjective embodiment, as experienced by the patient. In other words, the ambiguity of the post-transplant immunosuppressed body has not been explored from the patient's perspective and their own embodied experiences and negotiations of this state.

The subjective and private post-transplant body

Our explorations have now brought us to this point – what is missing from this biomedical network of transplantation, immunosuppression and compliance? We believe the answer is the most important voice of all – that of the patient. While it may be argued the patient's experiences have been heard through medicalized discourses of quality of life and non-compliance,

the issue is not that straightforward. Namely, what we have is a network of biomedical discourse wherein the patient, their experiences, their survival and their life, are simplistically relegated to compliance or non-compliance with medical regimens. Thus, work undertaken to date approaches the issue of patient compliance almost exclusively from the clinician's perspective, defining it in terms that are important to the healthcare professional rather than the patient. Few studies in the entire health corpus have explored the subjective notion of compliance from the patient's point of view. Therefore, despite extensive compliance literature, the voice of the immunosuppressed patient and the socio-cultural context in which they are embedded is noticeably absent. We plan to rectify this situation in our future research. For now, however, we would like to explore some sociological understandings of the subjective, embodied experience. While this literature does not focus explicitly on the post-transplant, immunosuppressed body, this initial theoretical analysis will provide some insight into how it might be understood and contextually experienced.

The debate about the terminology used with respect to patients' alignment to medical discourse highlights the focus that has been placed on clinician understanding of the concept, rather than that of the patient. In their work, Laederach-Hofmann and Bunzel (2000) suggest the terms 'compliance' and 'adherence' often indicate an unequal relationship between the doctor and patient, where the patient is viewed as passive and solely responsible for any behaviour that contravenes medical advice. This dichotomous relationship is based upon power and control (Baines et al., 2005). In recognition of this imbalance, the terms 'concordance' and 'non-concordance' have recently been posited by the healthcare profession as more desirable, suggesting doctor-patient consensus and patient empowerment rather than patient failure. For Laederach-Hofmann and Bunzel (2000), however, 'compliance' does not subvert the patient, as it implies a certain knowledge and awareness. In this conception, patient non-compliance cannot rest solely on the patient's shoulders, as compliance is measured in relation to patient behaviour that is consistent with a 'required and necessary' medical regimen (Barber, 2002).

We dispute these assertions and again point to shortcomings in compliance and adherence-based research. Even if patient compliance with medical regimens is concerned with health knowledge, this knowledge is viewed only in biomedical terms. For example, if the patient fails to take their imm-unosuppressive drugs regularly, their 'non-compliance' is interpreted as self-irresponsibility in choosing 'certain death' over 'certain life'. As our examinations demonstrate, patient non-compliance with medical regimens indicates to the healthcare professional a need for biomedical education, which will enable them to become an autonomous agent aligned with biomedical discourses. Consequently, the focus remains on patient behaviour; their failure to change and adhere to medical regimens; and the consequent negative outcomes perceived to result from such irresponsibility. Hence, medical compliance, patient empowerment and autonomy and their

quality of life, are predicated upon a medicalized model of self-regulation, which, as defined and mediated by medical expertise, is accorded the highest importance.

While the reasons health professionals have positioned patient behaviour in these ways are understandable, such an approach fails to recognize the patient's own perceptions, knowledge and experiences. Here, a conflict between the individual (subject) and the biomedicalized (object) body arises. Namely, patient non-compliance in the biomedical framework is viewed simplistically as medicinal, behavioural and attitudinal, and undervalues the complex multiplicities of difference that patients bring to biomedical encounters. In other words, patient non-compliance is medicalized through interventionist strategies, even though patient non-compliance may have no connection to medicine or their own health. Thus, the provision of healthcare should be a multidimensional process between the healthcare professional, the institution and patient, where each, and not just the renal transplant recipient, may need to adapt and change their expectations to facilitate a mutually desirable outcome. This approach may also highlight the ways in which patient compliance and non-compliance are socially constructed through a narrowed lens of biomedical knowledge, regimens and procedures. We have argued earlier that patient compliance with prescribed medical regimens may diminish or compromise quality of life and the lived body. By understanding compliance through lenses other than biomedical frameworks, we can see that compliance literature is not actually concerned with patient compliance as such. It is about power and control, and where these are most appropriately located. By focusing on patient insufficiencies and a patient's need for education and change, it is evident that the healthcare profession believes that power, knowledge and control are best located in the hands of the biomedical establishment and healthcare professionals. Patient autonomy is subsequently judged as either positive or negative and is based upon their behavioural relationship to medicalized control, which serves to continually produce and reproduce the rhetoric of good (compliant) and bad (non-compliant) patient. We will return to these points soon.

With these considerations in mind, we agree with Martins that both adherence and compliance, 'judge the patient behavior in ways that carry detrimental consequences for the patient and ... fail to engage a more robust notion of context' (2005: 75). In addition, the desire for patient compliance with medical regimens presumes agency and autonomy in the role of patient. This is not the case. Rather, patient compliance with medical regimens involves an individual's sacrifice of life (Martins, 2005), body, self and identity. These sacrifices occur by resigning knowledge and control to the medical 'other' (Martins, 2005). As a result, power is withdrawn from the individual, who is simply reduced to being a biologically immunocompromised and post-transplant body. In other words, the desire of the healthcare profession for patient compliance is only concerned with

an objectified and medicalized body, and not the subjective experience of lived embodiment. The ability to decide one's own quality of life, including self-sacrifice and self-determination, is generally not considered. That is, patient compliance with post-transplant medical regimens could, from the patient's perspective, compromise their quality of life rather than enhance it. It is not surprising that patients are 'non-compliant' when their social and embodied human lives are disregarded in such a reductionist manner.

Significantly, these studies on the experience of immunosuppression also focus exclusively on the body as static. The inference is that the body is unchangeable and operates simply as a protective boundary from outside influences. Therefore, what is external to the body is perceived as a dangerous threat, which the immunocompromised individual needs to deal with by complying with a medical regimen. Non-compliance, as the antithesis of compliance, is viewed as choosing death over life; the pathological over normal; illness over health; and the undesirable over the desirable. These medicalized dichotomies, however, are not necessarily the everyday embodied reality of the patient. Rather, the relationship between the immune system and the body is complicated and ambiguous, intimately involving things external to the body on an everyday basis other than infectious 'threats'. When one considers the experience of immunosuppression, these complexities could be numerous. For example, accepting a foreign renal graft involves blurring the self and other. This experience is heightened further through natural and unnatural transgressions in immunosuppression. With or without the immunocompromised experience, however, the body is fluid and open to the outside world (Martins, 2005). Therefore, the everyday 'lived' reality of embodiment blurs biomedical hierarchical binaries. At the same time, we do not know if immunocompromised transplant recipients actually experience their bodies in this fashion.

While biomedical interventions and technologies have destabilized the individual body and privileged the biomedical and objectified body, the post-transplant body remains attached to individual people as subjects, who need to negotiate and manage the biomedical discourse in which they are now embedded. As mentioned previously, this management occurs in a particular socio-cultural context, and not simply in a biomedical framework. In particular, the meanings of immunosuppressed bodies produced by biomedical technologies and 'experts' are not necessarily meaningful or recognizable to the renal transplant patient, as biomedical interventions may construct the individual in ways that do not align with the patient's self-recognition and their embodied, lived experience.

In asserting the body as a social phenomenon however, we are not ignoring that the body has a biological component. Rather, bodies are social, material and biological constructions, and biomedicine has a socially acknowledged position in understanding the medically altered body. Therefore, meanings attributed to bodies by medical technologies and individual experiences of illness are crucial in the construction of self and social identity (Kelly

and Field, 1996), meaning the body can be experienced simultaneously as a medicalized object and an embodied subject. This multiple and complex nature of self and identity illustrates that the attention of health professionals should not be simplistically focused on the biological body, where the current aim is to align patients to biomedical discourses. In turn, sociologists should not be solely concerned with the social and material body. Rather, we need understandings of how and when the post-transplant and immunosuppressed body is experienced individually as object and subject, and when it is experienced simultaneously as object and subject. In other words, we need both a sociological and medical framework in which both the biological and social bodies are considered. Through such an approach, we need also to explore how these complexities intersect with the various complexities and understandings of being an immunosuppressed, post-renal transplant recipient.

Conclusion

The goal of kidney transplantation is to improve the quality of life of patients in chronic renal failure. Nonetheless, renal recipients must make enormous lifestyle changes to maximize their chances of survival and good health while undergoing lifelong immunosuppression. From a healthcare perspective, this includes patient compliance with medical regimens. As we have explored, biomedical discourse on patient compliance universalizes and mechanizes the body and its experiences, ignoring multiplicity, complexity and context. In addition, compliance rhetoric only targets one body – the biological body as diagnosed through and determined by medical expertise and technologies – and undermines the material and social body. This dualistic and hierarchical structure of privilege can only understand the body as a manipulative object, which can be rendered as obedient through appropriate medical manipulation and intervention via the healthcare professional. This medicalized approach to the body, however, fails to understand how immune systems, immunosuppression and transplantation are lived experiences of subjective embodiment. It is necessary that healthcare professionals maintain awareness of the individuals who have their own views, negotiations and practices of their complex body, without an impetus to ‘intervene’ or ‘instil change’ in patient behaviour. The reduction of the body to a biological and mechanistic object in need of ‘expert’ intervention does a great disservice to all concerned in renal transplantation.

Our argument here is that becoming a renal transplant recipient and subsequently being immunosuppressed involves the adoption of norms and an acceptance of judgements that often do not originate with the individual concerned. For those labelled as ‘non-compliant’, medical regimens may be the imposition of normative ideals and practices through a biomedically mediated framework for self-care behaviour which the patient may not identify with.

We want to look at the competing forces enacting on and of the body, and the contexts in which these occur. We acknowledge the close relationship between the lived experience of the social, biological and material body, and understand these are important in identity construction and a patient's everyday reality. In the words of Shildrick, 'corporeal and ontological anxiety [*sic*] are inseparable' (2001: 159). We want to understand the immunosuppressed body as a lived and embodied experience, not simply as a conceptual or theoretical undertaking which unfortunately, due to the lack of empirical research, we have been restricted in doing here. It is necessary to 'capture how people live the discourse ... (to view) people's bodies as meeting places for different figures of thought and practices' (Lundin, 1999: 5). When biological boundaries such as immune systems are blurred or effaced, 'then normative boundaries and individual self images' (Lundin, 1999: 6) are also renegotiated. Not only is the material body complicated, so is the biological body. Therefore, through our future research, we seek to understand the social, material and biological bodies in the post-transplant, immunosuppressed experience, and the intersections that exist between them. We seek the delicate balance in the complex network of transplantation, immunosuppression and compliance. As such, we are not only concerned with the 'lived' experiences and intricacies of the material and biological bodies, but also the complications that exist between them and the multiple contextual experiences of 'being' post-transplant and immunosuppressed. We believe that through such understandings, a common ground can be forged between the medical establishment and the immunosuppressed post-transplant individual. We have set ourselves no easy task.

References

- Baines, L.S., Zawada, E.T., Jr and Jindal, R.M. (2005). Psychosocial profiling: A holistic management tool for non-compliance. *Clinical Transplantation*, 19(1), 38–44.
- Barber, N. (2002). Should we consider non-compliance a medical error? *Quality and Safety in Health Care*, 11(1), 81–4.
- Birke, L. (1994). *Feminism, animals and science: The naming of the shrew*. Buckingham: Open University Press.
- Birke, L., Bryld, M. and Lykke, N. (2004). Animal performances: An exploration of intersections between feminist science studies and studies of human/animal relationships. *Feminist Theory*, 5(2), 167–83.
- Brenner, M.J., Tung, T.H., Jensen, J.N. and Mackinnon, S.E. (2002). The spectrum of complications of immunosuppression: Is the time right for hand transplantation? *Journal of Bone and Joint Surgery*, 84(10), 1861–70.
- Bunzel, B. and Laederach-Hofmann, K. (2000). Solid organ transplantation: Are there predictors for posttransplant compliance? A literature review. *Transplantation*, 70(5), 711–16.
- Burke, A. (2003). Medical management of the liver transplant patient. *Graft*, 6(2), 136–44.

- Chisholm, M.A., Mulloy, L.L., Jagadeesan, M. and DiPiro, J.T. (2001). Impact of clinical pharmacy services on renal transplant patients' compliance with immunosuppressive medications. *Clinical Transplantation*, 15(5), 330–6.
- Claeson, B., Martin, E., Richardson, W., Schoch-Spana, M. and Taussig, K.-S. (1996). Scientific literacy, what it is, why it's important, and why scientists think we don't have it: The case of immunology and the immune system. In L. Nader (Ed.), *Naked science: Anthropological inquiry into boundaries, power, and knowledge*, pp. 101–18. New York: Routledge.
- Dew, M.A., Myaskovsky, L., DiMartini, A.F., Switzer, G.E., Schulberg, H.C. and Kormos, R.L. (2004). Onset, timing and risk for depression and anxiety in family caregivers to heart transplant recipients. *Psychological Medicine*, 34(6), 1065–82.
- Donovan, J.C.H., Rosen, C.F. and Shaw, J.C. (2004). Evaluation of sun-protective practices of organ transplant recipients. *American Journal of Transplantation*, 4(11), 1852–8.
- Dwyer, J. (1993). *The body at war: The story of our immune system*, 2nd edn. St Leonards: Allen & Unwin.
- Fireman, M., DiMartini, A.F., Armstrong, S.C. and Cozza, K.L. (2004). Immunosuppressants. *Psychosomatics*, 45(4), 354–60.
- Fukunishi, I., Sugawara, Y., Takayama, T., Makuuchi, M., Kawarasaki, H. and Surman, O.S. (2001). Psychiatric disorders before and after living-related transplantation. *Psychosomatics*, 42(4), 337–43.
- Green, C.J. (2003). Organ transplantation. In W.J. Phipps, F.D. Monahan, J.K. Sands, J.F. Marek and M. Neighbors (Eds.), *Medical-surgical nursing: Health and illness perspectives*, 7th edn, pp. 1686–716. St Louis: Mosby.
- Haraway, D.J. (1991). *Simians, cyborgs, and women: The reinvention of nature*. New York: Routledge.
- Jowsey, S.G., Taylor, M.L., Schneekloth, T.D. and Clark, M.M. (2001). Psychosocial challenges in transplantation. *Journal of Psychiatric Practice*, 7(6), 404–14.
- Kelly, M.P. and Field, D. (1996). Medical sociology, chronic illness and the body. *Sociology of Health and Illness*, 18(2), 241–57.
- Kreiger, N.R. and Emre, S. (2004). Novel immunosuppressants. *Pediatric Transplantation*, 8(6), 594–9.
- Laederach-Hofmann, K. and Bunzel, B. (2000). Noncompliance in organ transplant recipients: A literature review. *General Hospital Psychiatry*, 22(6), 412–24.
- Levenson, J.L. and Olbrisch, M.E. (2000). Psychosocial screening and selection of candidates for organ transplantation. In P.T. Trzepacz and A.F. DiMartini (Eds.), *The transplant patient: Biological, psychiatric and ethical issues in organ transplantation*, pp. 21–41. Cambridge: Cambridge University Press.
- Lundin, S. (1999). The boundless body: Cultural perspectives on xenotransplantation. *Ethnos*, 64(1), 5–31.
- McCarthy, A. (2005). A rebellious distemper: A Foucaultian history of breast cancer to 1900. Unpublished PhD thesis, Queensland University of Technology.
- Martin, E. (1994). *Flexible bodies: Tracking immunity in American culture – from the days of polio to the age of AIDS*. Boston, MA: Beacon Press.
- Martins, D.S. (2005). Compliance rhetoric and the impoverishment of context. *Communication Theory*, 15(1), 59–77.

- Merck manual. (2006a). Biology of the immune system. *Merck manual home edition*. Retrieved 7 March 2006 from <http://www.merck.com/mmhe/print/sec16/ch183/cha183a.html>
- Merck manual. (2006b). Immunology of rejection. *The Merck manual of diagnosis and therapy*. Retrieved 7 March 2006 from <http://www.merck.com/mrkshared/mmanual/section12/chapter149/149b.jsp>
- Merck manual. (2006c). Kidney transplantation. *The Merck manual of diagnosis and therapy*. Retrieved 7 March 2006 from <http://www.merck.com/mrkshared/mmanual/section12/chapter149/149c.jsp>
- Merck manual. (2006d). Transplantation. *The Merck manual of diagnosis and therapy*. Retrieved 7 March 2006 from <http://www.merck.com/mrkshared/mmanual/section12/chapter149/149a.jsp>
- Moloney, F.J., de Freitas, D., Conlon, P.J. and Murphy, G.M. (2005). Renal transplantation, immunosuppression and the skin: An update. *Photodermatology, Photoimmunology & Photomedicine*, 21(1), 1–8.
- Otis, L. (1999). *Membranes: Metaphors of invasion in nineteenth-century literature, science and politics*. Baltimore, MD: Johns Hopkins University Press.
- Rauch, J.B. and Kneen, K.K. (1989). Accepting the gift of life: Heart transplant recipients' post-operative adaptive tasks. *Social Work in Health Care*, 14(1), 47–59.
- Sherwood, L. (1993). *Human physiology: From cells to systems*, 2nd edn. Minneapolis, MN: West Publishing Company.
- Shildrick, M. (2001). Vulnerable bodies and ontological contamination. In A. Bashford and C. Hooker (Eds.), *Contagion: Epidemics, history and culture from small pox to anthrax*, pp. 153–67. London: Routledge.
- Wilkins, F., Bozik, K. and Bennett, K. (2003). The impact of patient education and psychosocial supports on return to normalcy 36 months post-kidney transplant. *Clinical Transplantation*, 17(supp. 9), 78–80.

Author biographies

PETA S. COOK is a sociologist at the Queensland University of Technology, Centre for Social Change Research. Her research interests include the sociology of health and illness, science, technology, non-humans, social policy, social change and the body. Her current research projects examine the local/global tensions of xenotransplantation (animal-to-human transplantation) as a medical tourist therapy (xenotourism); and an empirical examination of the socio-cultural aspects of xenotransplantation in Australia.

ALEXANDRA MCCARTHY is a registered nurse and sociologist located at Griffith University, School of Nursing and Midwifery. Her teaching, research and political activities focus upon the clinical and sociological aspects of renal and oncology practice. Her current research projects investigate a range of issues related to compliance and self-care in dialysis patients; and the long-term socio-cultural and physiological implications of cancer survivorship.